

Company number: 04899036

Registered charity number: 1101971

Registered charity number (Scotland): SC043852

**ACTION DUCHENNE LIMITED**  
**ANNUAL REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**FOR THE YEAR ENDED 31 MARCH 2021**

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**ACTION DUCHENNE LIMITED**  
**ANNUAL REPORT AND FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**ADMINISTRATIVE AND STATUTORY DETAILS**

<b>Board of Trustees</b>	Mark Silverman Gary Fegan Roger Cockerton (Treasurer) Dr Tina Flatau Robert Laid Simon Dadd Victoria Penrice Ellen Lambrix
<b>National Director</b>	Florence Boulton
<b>Scientific Advisory Board</b>	Dame Professor K Davies – Chair Professor M Wood – Vice Chair
<b>Registered office</b>	CAN Mezzanine 49-51 East Road Hoxton London N1 6AH
<b>Independent Examiners</b>	Simpson Wreford LLP Wellesley House Duke of Wellington Avenue Royal Arsenal London SE18 6SS
<b>Company number</b>	04899036
<b>Charity number</b>	1101971 SC043852 (Scotland)
<b>Solicitors</b>	Morgan Cole Bradley Court Park Place Cardiff CF10 3DR
<b>Banks</b>	Barclays Bank PO Box 3 77 North Street, Keighley BD21 3SA  The Co-operative Bank Plc PO Box 250 Skelmersdale N3 6WT

## ACTION DUCHENNE LIMITED

### MESSAGE FROM THE NATIONAL DIRECTOR FOR THE YEAR ENDED 31 MARCH 2021

The year 2020/21 has been a monumental year for Action Duchenne. We could define it as the year of **bringing support, care and education to life**. The winds of change have pervaded every aspect of Action Duchenne's operations, affecting not only our charity's activities, but our staff and entire community; the children, young people and adults living with Duchenne and their families and supporters. Not even the management has been immune to it. It is my absolute pleasure to give you a brief walk through our major milestones of the year and to provide you with a taste of the surprising achievements you will encounter throughout the report.



#### The dedicated Action Duchenne team

The heart of any great organisation lies with its people. We are truly appreciative of our team of dedicated and passionate staff at Action Duchenne who have put forth a tremendous effort in propelling the organisation forward with many new launches, transitions and projects this past 12 months.

#### Supporting families

In 2020/21, we have:

- supported over 2,000 young people, adults and their families through our direct and bespoke support calls, video chats and online meetings;
- delivered over 30 support webinars, which covered important topics from physiotherapy, learning and behaviour to making the most of online appointments;
- established 6 peer-to-peer support groups for grandparents, Mums, Dads and young people living with Duchenne have gone from strength to strength;
- wowed over 120 children and young people in our virtual magical grotto to meet Father Christmas;
- shared 37 volunteer contributors' personal lived experiences and blog posts.

#### International Conference 2020/21

Action Duchenne International Conference was the preeminent Duchenne event in the UK. The 19th global conference brought together the best researchers in Duchenne muscular dystrophy from across the world. The event attracted over 700 families, clinicians, therapists, researchers, pharmaceutical companies and, most importantly, those living with Duchenne from at least 50 nations. Families and supporters were able to meet and learn about all aspects of the condition from international experts, as well as to find out from other families and those living with Duchenne, how to get the best life possible. For academics and clinicians, this event provided the opportunity to network, along with discussing the latest findings in genetic research and sharing expertise in optimal standards of care.





MESSAGE FROM THE NATIONAL DIRECTOR  
FOR THE YEAR ENDED 31 MARCH 2021

### Supporting research

We have continued on our proven track record of funding state-of-the art translational Duchenne research. Funding a range of projects this financial year, we have;

- supported the UNITE-DMD programme, alongside Muscular Dystrophy UK and AFM Telethon. This project aims to develop and test a gene therapy for Duchenne muscular dystrophy, in a clinical trial. An update in late 2020 reported that Genethon would begin a clinical trial at a French site, with UK Sites opening once ethical approval was secured. As part of our response to the pandemic, we renegotiated our funding of the UNITE-DMD programme to reduce our total commitment to £200K.
- completed a multi-year Clinical Trials Lectureship project at Newcastle University which we funded alongside other Duchenne charities (Alex's Wish, Duchenne UK, Duchenne Now, Duchenne Research Fund, Joining Jack and Harrison's Fund), demonstrated the potential of this approach - funding a multi-year Clinical Trials Lectureship that enabled the holder to develop the centre's clinical trials programme.
- despite some delays (due to labs being closed during lockdown, the project that we awarded to Dr Yung Yao Lin at Queen Mary University London is progressing well. Together with Barts Charity, we are funding an innovative project that aims to develop techniques to combine stem cell and gene-editing technologies in Duchenne. The researchers are currently writing up their results for publication in a scientific journal early next year.
- founded our Big Ideas Fund - an innovative scheme that aims to invest small amounts of money in early stage research projects. For parents of a child affected by Duchenne, knowing that a scientist may have an idea that can't be tested due to a lack of funding is devastating. An untested idea might represent a life changing treatment. Or even, the hope for all Duchenne parents, a cure...Our Big Ideas Fund will award small top-up grants to enable researchers to bring those novel, untested ideas to the lab. Donations we receive for the fund are restricted with every penny donated going towards funding exciting new research projects.
- continued our ongoing curation and support of the UK DMD registry as a key part of our research strategy. The registry has more than 2,000 people registered including more than 1,000 people living with Duchenne and is governed by a Steering Committee chaired by Dr Michela Guglieri (Institute of Human Genetics, Newcastle University). The UK DMD Registry is designed to respond to pharmaceutical feasibility studies to help drug developers identify whether it is possible to run a clinical trial in the UK. Over the next financial year, we plan to launch a new platform that will make longitudinal data collection possible.

### Bringing our whole community together

In 2020/21, we had the pleasure of working with 18 regular volunteers giving their time and expertise on a range of tasks, from website, HR support, impact measurement, webinars, writing blogs to researching fundraising opportunities.



Our work also relies on voluntary donations from individuals, groups and companies. It is through your generosity that Action Duchenne continues to play a significant role in the support of our Duchenne community, helping children, young people and adults living with Duchenne to participate in our support and education projects that will lead them to become more independent, increased life satisfaction and quality of life.

**MESSAGE FROM THE NATIONAL DIRECTOR  
FOR THE YEAR ENDED 31 MARCH 2021**

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**Rebuild, refocus and reinvest - Action Duchenne Strategy 2021-2024**

Action Duchenne puts our Duchenne families in the lead, so that they can define and refine our work and our role. Our 2021-2024 strategy plan provides a clear roadmap for our future strategy and marks the beginning of a new and exciting chapter.

In the next 3 years, we will focus on increasing support and delivering more innovative projects. We will achieve this by delivering projects that encourage the Duchenne community to use their passion, skills and experience to support, inspire, and empower each other. We will use our positive public image and messaging to engage business sponsors to fund our vital projects by:

- putting value at the heart of our Duchenne families and their supporters;
- re-establishing our science and research communication service;
- understanding what our supporters value most about our work;
- expanding our support and education services to explore new support opportunities;
- building our stakeholder engagement networks with our members, supporters and volunteers;
- developing an impact and evaluation framework for continual improvement;
- being transparent about our work so everyone can be confident that Action Duchenne is acting responsibly and investing our resources wisely.

**Looking to the future**



Our future success will be defined by projects that reach across the UK and internationally to improve care; provide families with the knowledge, education and support they need throughout their Duchenne journey; and provide people living with Duchenne with opportunities to attend university, find a job and reach their full potential in society.

All in all, 2020/21 could not have been a better time for me to take the reins at Action Duchenne. I extend my heartfelt gratitude to our volunteers, Patrons, Ambassadors and the Board of Trustees, for their passion and commitment, for supporting me at the International Conference, designing our new, much-needed 'All-through Support' project, enabling the charity to bring the life-changing opportunity of the support to so many children, young people, adults and families in the UK and globally, at the most important stages of their Duchenne.

We truly are stronger together. Action Duchenne is committed to supporting the future for everyone living with Duchenne... Another busy year ahead!

  
.....  
Florence Boulton  
National Director



**ACTION DUCHENNE LIMITED**  
**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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The Trustees present their report and the financial statements for the twelve months ended 31 March 2021 which have been prepared in accordance with accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

**Reference and administrative details**

Action Duchenne Limited is registered under the Companies Act as a company limited by guarantee (company number 04899036). The charity registration number is 1101971 (England and Wales) and SC043852 (Scotland). The registered office address which is also the principal office address is CAN Mezzanine, 49-51 East Road, London N1 6AH.

The governing documents are the Company's Memorandum and Articles of Association. Each of the members has undertaken to contribute up to £1 in the event of dissolution. The board of Trustees manages the company on behalf of the members and the authority to appoint and remove Trustees is vested in the board.

The following persons were Directors and Trustees during the year:

Mark Silverman  
Gary Fegan  
Dr Tina Flatau  
Robert Laid  
Simon Dadd  
Roger Cockerton (Treasurer)  
Victoria Penrice  
Zachary Fargher (resigned 29 July 2021)  
Ellen Lambrix (appointed 29 September 2021)

The Board have agreed a process of Trustee Training and Induction, so that new and current Trustees are briefed with their legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the committee and decision-making processes, the business plan and recent financial performance of the Charity and any changes therein. This includes the delivery of Charity Commission publications explaining their role.

The Trustees would also like to thank all Patrons and Trustees, past and present, who have given their time and energy to Action Duchenne.

**ACTION DUCHENNE LIMITED**  
**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**Introduction**

The charity landscape changed dramatically in the three years up to 2020/21, mainly due to the proliferation of new UK Duchenne charities. This required Action Duchenne to review its own offering and purpose to ensure it retained a place in the changed community.

In 2020/21 we have refined the operational plan after consultation with supporters, families, Patrons, Ambassador and trustees, and input from all the team members. We have established a strategic roadmap for 2021-24, allowing us to know the direction we are meant to follow in relation to an individual component of our operations (for example, research, education, support, campaigning and operational management).

There are several key challenges that we have tried to address in 2020/21:

- securing sustainable funding in the medium to long term
- ever-changing landscape for communication, fundraising and support makes moving towards a more integrated, digital way of working imperative
- competing successfully in a competitive market

**About us: our vision and objectives**

Action Duchenne has a very clear vision: a world where lives are no longer limited by Duchenne muscular dystrophy.

We have three core objectives:

- Developing effective treatments for all by funding research, supporting clinical trials and campaigning for access.
- Building a community by uniting and supporting families, educating about Duchenne and raising the profile of the condition.
- Striving for a more inclusive society promoting the importance of human equality, day to day acceptance of disability and accessibility.

**What is Duchenne?**

Duchenne muscular dystrophy is a rare genetic condition caused by mutations in the dystrophin gene, which prevent production of a vital muscle protein called dystrophin. The lack of dystrophin makes muscles more susceptible to damage and leads to muscle wasting over time. Duchenne is usually diagnosed around the age of 4, and people living with the condition experience progressive muscle weakness. They typically need to use a powered wheelchair from their early teens, and since the heart and breathing muscles are affected most will require a ventilator in their twenties.

When Action Duchenne was founded in 2001, the average life expectancy for a young person living in the UK with Duchenne was late teens. It is now late 20s with more people than ever living into their 30s and 40s.

There is no cure.

**ACTION DUCHENNE LIMITED**  
**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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### **Why Action Duchenne?**

- ❖ **Committed:** staff, trustees and patrons, along with a supportive network of volunteers and partner organisations
- ❖ **Rigorous:** governance procedures, policies and processes are well controlled in line with regulatory frameworks and best practices
- ❖ **Collaborative:** working closely with trustees, stakeholders and national and international partner organisations to achieve goals
- ❖ **Innovative:** projects and programmes are created to satisfy an unmet need
- ❖ **Influential:** within the Duchenne community, pharmaceutical, health and social care sectors
- ❖ **Proactive:** forging partnerships with funders, organisations, corporates and individuals to drive fundraising, revenue, and find new income streams
- ❖ **Reporting:** established systems to evaluate, report and feedback impact, communicating more effectively to all stakeholders

### **Our reflection**

Action Duchenne is at the heart of the Duchenne community. 50% of our staff and Trustees have a child living with the condition and this provides real, on-the-spot expertise on what the families we support need and the situations they face. We have had some major successes. We brought together the group of scientists who developed the 'exon skipping' drugs that offer hope for some living with Duchenne; our disease registry has put the UK at the forefront of clinical trials; our research funding has given more than 130 people the chance to take part in a clinical trial and we are currently funding a gene therapy clinical trial so even more families can be offered this opportunity.

Our support team talks to over 2,000 families living with Duchenne every year. We might help families to apply for benefits, attend meetings at schools alongside families or simply listen as families talk about their child's condition. Our work provides a vital lifeline to families, and we aim to help every single person and family affected by the condition. Following diagnosis, parents often say "the only person who understands what I'm going through is another Duchenne parent".

The team works hard to bring families together, to support each other. We organise the largest Duchenne conference in Europe, bringing families from across the UK together with expert clinicians, researchers and drug developers. We work with others wherever possible and have acted as a springboard for other patient groups.

### **Financial Review**

The accounting period reverted to 12 months following the previous period that was extended to 17 months to move our financial year so our annual international conference (in November) falls in a single financial year.

In 2020/21 the Charity had a net surplus for the year of £126,477 following a deficit of £23,538 in the previous year. The year has been characterised by a challenging environment across the charity sector; for Action Duchenne this materialised as a reduction in donations and legacies received. Scientific research and grants payable decreased by 53.5% from £643,779 to £299,403 which compounded the surplus for the year.

Income was £494,338 in 2020/21 (12 month period) and £758,434 in 2018/20 (17 month period). With amounts generated from donations and legacies decreasing 43.1%, income from other trading activities decreasing 63.5% and an increase in income from charitable activities of over 700%.

**ACTION DUCHENNE LIMITED**  
**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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Expenditure on charitable activities was £326,138 in the 12 month period (2018/20, 17 months: £685,441), including allocated support costs. This represents 88.7% of total expenditure, compared to 87.7% in the previous year. Of this, £299,403 was spent on research and grants payable (2018/20: £643,779). As well as the research organisations listed above, this includes UPPMD membership and Genetic Alliance UK membership.

Operational costs continue to be managed tightly, and the National Director has initiated a focused programme of work to correct the fall in charitable income in particular.

#### **Loan Borrowings**

During the year, the Charity secured a £50,000 Bounce Bank loan under the Coronavirus government-backed lending scheme.

#### **Reserves**

The Finance Committee, on behalf of the Board of Trustees, monitors the level of unrestricted reserves in the general fund, which is compared to the minimum level of required reserves calculated in accordance with the reserves policy. This is based on three months of charity expenditure of £92,000, which is aimed at providing cover in the event of a sudden reduction in income:

- To allow time for reorganisation in the event of a downturn in income.
- To protect ongoing work programme
- To allow the Charity to meet its objectives.
- To ensure the General funds are allocated to meet the Charity's Aims and Objectives.

Unrestricted reserves are £218,246 up from £91,600 in March 2020 and restricted reserves are £21,259 (2020: £21,428). The unrestricted reserves exceed the minimum required under the policy.

#### **Grant Making Policy**

The Charity has a programme of grant making to provide funds for new research towards finding viable treatments and ultimately curing Duchenne muscular dystrophy. Our research strategy sets out five key areas, where we will focus our investment in research going forward:

- Innovation – we will co-fund novel research projects
- Outcome measures and natural history data
- Investing in tissue collection and biobanking
- Standards of Care – continuing our long-standing involvement in supporting the best possible multidisciplinary standards of care
- Maintaining the UK DMD Registry

The rapidly changing developments in international research demand a constant updating of the charity's grant making policy. Our peer reviews grant applications as part of a two-stage review process and systematically reviews and agrees its research and grant making policy during the development of its annual business plan.

#### **Investment Policy**

The Charity's assets will be invested in accordance with the Trustee Act 2000 and the trust instrument. Any investments will be managed prudently and in such a way as to provide sufficient income to enable the charity to carry out its purposes effectively both in the short term and over the longer term. In order to spread the level of risk, no single investment or account should exceed 50% of the total funds held by the charity without the agreement of the Finance Committee.

**ACTION DUCHENNE LIMITED**  
**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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While the Charity's overall investment policy has been set by the Board of Trustees as a whole, responsibility for ongoing investment matters has been delegated to the Finance Committee.

**Internal control and processes**

The systems of internal control, put in place by the Trustees, are designed to provide reasonable but not absolute assurance against material misstatement or loss and include:

- Financial reports are reviewed at the quarterly Board meetings as part of measures to ensure that the resources of the Charity are effectively allocated and utilised
- Expenditure approval limits beyond which approval must be sought from the National Director and then the Finance Committee and/or the board of Trustees
- The management team prepare a business plan with internally audited yearly accounts and projections of budget expenditure at the end of each year. This is fully discussed by the Finance Committee and then at a specially convened meeting of the Board of Trustees
- The Finance Committee is responsible for overseeing the annual independent examination of the accounts by Simpson Wreford LLP
- Regular consideration by the Finance Committee of financial results, variances from budgets, forecasts and performance indicators
- Chain of command overseen by the Treasurer, delegation of authority and segregation of duties
  
- Ensuring that the Charity submits Annual Reports to the Charity Commission and Companies House in line with current standard reporting procedures
- Trustees are encouraged to undertake Trustee and governance training by accredited providers of education to the charity sector
- The Board maintains a forward programme of process/policy update and creation, this includes policies for:
  - Identification and management of risk
  - HR
  - Safeguarding
  - Trustee and volunteer roles and responsibilities
  - Charity procedures (including financial control)
  - Equal opportunities
  - Social media and digital/electronic communications

The Board of Trustees meet face to face or via remote conferencing at least four times a year. While the Charity aims to involve parents and those living with Duchenne muscular dystrophy as members of the Board of Trustees, a balance is sought by recruiting non-family members who have other scientific, business and professional expertise. The Board is divided into four sub committees, each with specific terms of reference: corporate engagement, audit, finance & risk, delivery & research, and conference.



**ACTION DUCHENNE LIMITED**  
**REPORT OF THE TRUSTEES**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**Trustees' Responsibilities**

The Trustees (who are also Directors of the charity for the purposes of company law) are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- there is no relevant independent examination information of which the charitable company's independent examiner is unaware; and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant independent examination information and to establish that the independent examiner is aware of that information.

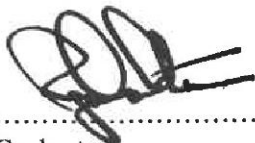
The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

**Independent Examiner**

Simpson Wreford LLP were reappointed as Independent Examiners during the year and have expressed their willingness to continue in that capacity.

The above report has been prepared in accordance with the special provisions of Section 419(2) of the Companies Act 2006 relating to small companies.

Signed on behalf of the Board of Directors.



.....  
Roger Cockerton  
**Treasurer**

Date: 8 December 2021

**INDEPENDENT EXAMINERS' REPORT**  
**TO THE TRUSTEES OF ACTION DUCHENNE LIMITED**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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I report on the accounts of the company for the year ended 31 March 2021, which are set out on pages 12 to 25.

**Responsibilities and basis of report**

As the charity's Trustees (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 (the '2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

**Independent examiner's report**

Since the company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- (1) accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
- (2) the accounts do not accord with those accounting records; or
- (3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
- (4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

**M Broder FCA**

**for and on behalf of Simpson Wreford LLP, Chartered Accountants**

Wellesley House  
Duke of Wellington Avenue  
Royal Arsenal

London  
SE18 6SS

Dated: 9 DECEMBER 2021

**ACTION DUCHENNE LIMITED**

**STATEMENT OF FINANCIAL ACTIVITIES**  
**(including statement of income and expenditure)**  
**FOR THE YEAR ENDED 31 MARCH 2021**

			12 mths to 31 March 2021 Total funds	17 mths to 31 March 2020 Total funds
	Notes	2021 Unrestricted funds	2021 Restricted funds	
<b>Income and endowments from:</b>	<b>4</b>			
Donations and legacies		217,844	5,000	222,844
Charitable activities		-	125,560	125,560
Other trading activities		128,874	-	128,874
Investments		32	-	32
Other - Government grants		<u>17,028</u>	<u>-</u>	<u>17,028</u>
<b>Total income</b>		<b><u>363,778</u></b>	<b><u>130,560</u></b>	<b><u>494,338</u></b>
<b>Expenditure on:</b>	<b>16</b>			
Raising funds:				
Cost of events and general fundraising		41,723	-	41,723
Charitable activities:				
Campaigning and education		16,041	-	16,041
Scientific and clinical research and grants payable		158,255	141,148	299,403
Improved management and medical care		<u>10,694</u>	<u>-</u>	<u>10,694</u>
<b>Total expenditure</b>		<b><u>226,713</u></b>	<b><u>141,148</u></b>	<b><u>367,861</u></b>
Net income/(expenditure)		<b>137,065</b>	<b>(10,588)</b>	<b>126,477</b>
Transfers between funds		<u>(10,419)</u>	<u>10,419</u>	<u>-</u>
<b>Net movement in funds</b>		<b><u>126,646</u></b>	<b><u>(169)</u></b>	<b><u>126,477</u></b>
<b>Reconciliation of funds</b>				
Balance at 1 April 2020		<u>91,600</u>	<u>21,428</u>	<u>113,028</u>
Balance at 31 March 2021		<b><u>218,146</u></b>	<b><u>21,259</u></b>	<b><u>239,505</u></b>

The notes on pages 15 to 25 form part of these financial statements.

**ACTION DUCHENNE LIMITED**  
**STATEMENT OF FINANCIAL POSITION**  
**AS AT 31 MARCH 2021**

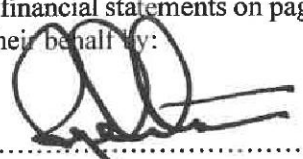
	Notes	2021	2020
		£	£
<b>Fixed assets</b>			
Tangible assets	5	1,920	1,135
Investments	6	<u>2</u>	<u>2</u>
		1,922	1,137
<b>Current assets</b>			
Debtors	7	51,093	43,867
Cash at bank and in hand		<u>396,747</u>	<u>98,374</u>
		447,840	142,241
<b>Current liabilities</b>			
Creditors due within one year	8	<u>(166,090)</u>	<u>(30,350)</u>
<b>Net current assets</b>		<u>281,750</u>	<u>111,891</u>
<b>Total assets less current liabilities</b>		283,672	113,028
<b>Creditors due more than one year</b>	9	<u>(44,167)</u>	<u>-</u>
<b>Net assets</b>	15	<u>239,505</u>	<u>113,028</u>
<b>Represented by:</b>			
Restricted funds	13	21,359	21,428
Unrestricted funds	14	<u>218,146</u>	<u>91,600</u>
		<u>239,505</u>	<u>113,028</u>

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the period ended 31 March 2021. No member of the company has deposited a notice, pursuant to section 476, requiring an audit of these accounts under the requirements of the Companies Act 2006.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

These accounts have been prepared in accordance with the provisions applicable to company's subject to the small companies' regime.

The financial statements on pages 13 - 25 were approved by the Trustees on 8 Dec 2021 and signed on their behalf by:

  
 .....  
 Roger Cockerton— **Trustee/Treasurer**

Registered charity number – 1101971

Registered charity – SC043852 (Scotland)

**ACTION DUCHENNE LIMITED**  
**STATEMENT OF CASH FLOWS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

	Notes	12 mths to 31 March 2021 Total £ (12)	17 mths to 31 March 2020 Total £ (17)
<b>Cashflows from operating activities:</b>			
<b>Net cash (used in)/provided by operating activities</b>	<b>19</b>	<u>299,765</u>	<u>(87,110)</u>
<b>Cashflows from investing activities:</b>			
Dividends, interest and rents from investments		33	228
Purchase of equipment		(1,425)	-
Purchase of investments		<u>-</u>	<u>-</u>
Net cash provided by/(used in) investing activities		<u>(1,392)</u>	<u>228</u>
Change in cash and cash equivalents in the reporting period		298,373	(86,882)
Cash and cash equivalents as at 1 April 2020	<b>20</b>	<u>98,374</u>	<u>185,256</u>
Cash and cash equivalents as at 31 March 2021	<b>20</b>	<u><b>396,747</b></u>	<u><b>98,374</b></u>

**ACTION DUCHENNE LIMITED**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**1. Accounting policies**

- a) Company information – Action Duchenne Limited is a company limited by guarantee, incorporated in England and Wales and registered as a charity with the Charities Commission and in Scotland. The principal and registered office is CAN Mezzanine, 49-51 East Road, Hoxton, London, N1 6AH.
- b) The financial statements have been prepared in accordance with accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Action Duchenne Limited meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

The financial statements are prepared in sterling, which is the functional currency of the company. Monetary amounts in the financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation long-term leasehold property and certain financial instruments at fair value or amortised cost. The principal accounting policies are set out below.

The effects of events relating to the twelve months ended 31 March 2021 which occurred before the date of approval of the financial statements by the Trustees has been included in the financial statements to the extent required to show a true and fair view of the state of affairs as at 31 March 2021 and the results for the year ended on that date.

- c) Going Concern – at the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.
- d) Donations and legacies are accounted for when receivable by the Charity. Revenue grants are credited to the Statement of Financial Activities (SOFA) when the Charity is considered to have entitlement to the assets. It is probable that the resources will be received, and the monetary value of incoming resources can be measured with sufficient reliability. If grants are related to a future donor-imposed period, the income is deferred until that period. Other income is accounted for on an accrual basis.
- e) Direct charitable expenditure includes the direct costs of the activities. Support costs are allocated per note 16 on the basis of time spent.
- f) Fundraising costs are the direct costs of obtaining funds, and attributable allocated support costs.
- g) Governance costs include those costs incurred in the governance of the Charity, such as independent examiners' fees.
- h) Programme related investments are included in the accounts at cost less amounts written off as grants payable.

**ACTION DUCHENNE LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2021**

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**1. Accounting policies (continued)**

- i) Fixed assets are only capitalised where their values exceed £500. Fixed assets are stated at cost and depreciation is calculated so as to write off the cost of an asset, less its estimated residual value, over the useful economic life of that asset at a rate of 25% reducing balance.
- j) Impairment of fixed assets - at each reporting date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).
- k) Debtors – trade and other debtors are recognised at the settlement amount due after trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.
- l) Cash and cash equivalents – include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.
- m) Financial instruments – the charity only has financial assets and liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.
- n) Creditors and provisions – are recognised at the point where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discount due. All expenditure is accounted for on an accruals basis and includes irrecoverable Value Added Tax.

Grants payable are payments made to third parties in the furtherance of the Charity's objectives. Single or multi-year grants are recognised as resources expended when a grant commitment is made without condition, or when the condition will not in practice allow the Charity to avoid the liability.

Performance related grants are charged to SOFA as performance conditions are met.

- o) Operating lease commitments – rentals paid under operating leases are charged on a straight-line basis over the lease term.
- p) Employee benefits – the cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.
- q) Pension scheme – the charity provides a defined contribution scheme for all new employees, the assets of which are held separately from those of the company in an independently administered fund. Contributions to this scheme are charged to the income and expenditure account as they become payable.
- r) Fund accounting – General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Restricted funds made to the charity are to be used in accordance with specific restrictions imposed by donors. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.



**ACTION DUCHENNE LIMITED**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

**2. Employees**

Costs to the company were as follows:

	<b>2021</b> <b>£</b> <b>(12 mths)</b>	<b>2020</b> <b>£</b> <b>(17mths)</b>
Gross wages:		
- projects	169,635	62,333
- non-projects	20,498	210,045
Staff pension	4,123	5,687
Employer's NI contributions	<u>14,315</u>	<u>23,061</u>
	<u><b>208,571</b></u>	<u><b>301,126</b></u>

The average number of full-time employees during the year was 6 (2020 - 7) analysed as follows:

	<b>2021</b> <b>Number</b> <b>(12 mths)</b>	<b>2020</b> <b>Number</b> <b>(17mths)</b>
Management - FTE	0.6	-
Research - FTE	0.6	1
Support - FTE	2.3	-
Fundraising - FTE	1.8	4
Advocacy/Campaigns - FTE	<u>0.7</u>	<u>2</u>
	<u><b>6</b></u>	<u><b>7</b></u>

There were no employees at Action Duchenne Limited whose remuneration exceeded £60,000.

**3. Net incoming resources is stated after charging**

	<b>2021</b> <b>£</b> <b>(12 mths)</b>	<b>2020</b> <b>£</b> <b>(17mths)</b>
Independent examination and accountancy fees	7,620	8,697
Depreciation	<u>640</u>	<u>378</u>

**ACTION DUCHENNE LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2021**

**4. Analysis of income and endowments**

	<b>Unrestricted funds £</b>	<b>Restricted funds £</b>	<b>2021 Total £ (12 mths)</b>	<b>2020 Total £ (17mths)</b>
<b>Donations and legacies</b>				
- Grants of a general nature	13,551	5,000	18,551	-
- Membership subscriptions	41,711	-	41,711	36,614
- Fundraising income	104,688	-	104,688	341,830
- Gift Aid	7,894	-	7,894	3,736
- Other	50,000	-	50,000	8,978
<b>Charitable activities</b>				
- Performance related grants	-	125,560	125,560	14,285
- Other	-	-	-	-
<b>Other trading activities</b>				
- Fundraising events	4,375	-	4,375	-
- Non-charitable trading activities	123,066	-	123,066	352,763
- Shop income	1,433	-	1,433	-
<b>Investments</b>	32	-	32	228
<b>Other – Government grants</b>	<u>17,028</u>	<u>-</u>	<u>17,028</u>	<u>-</u>
	<u>363,778</u>	<u>130,560</u>	<u>494,338</u>	<u>758,434</u>

**5. Tangible assets**

	<b>Computer Equipment £</b>	<b>Fixtures &amp; fittings £</b>	<b>Office equipment £</b>	<b>Total £</b>
<b>Cost</b>				
At 1 April 2020	25,147	1,098	6,839	33,084
Additions	<u>-</u>	<u>-</u>	<u>1,425</u>	<u>1,425</u>
31 March 2021	<u>25,147</u>	<u>1,098</u>	<u>8,264</u>	<u>34,509</u>
<b>Depreciation</b>				
At 1 April 2020	24,161	1,083	6,705	31,949
Charge for the year	<u>246</u>	<u>4</u>	<u>390</u>	<u>640</u>
At 31 March 2021	<u>24,407</u>	<u>1,087</u>	<u>7,095</u>	<u>32,589</u>
<b>Net book value</b>				
At 31 March 2021	<u>740</u>	<u>11</u>	<u>1,169</u>	<u>1,920</u>
At 31 March 2020	<u>986</u>	<u>15</u>	<u>134</u>	<u>1,135</u>

**ACTION DUCHENNE LIMITED**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

**6. Investments**

	2021 £	2020 £
<b>Programme related investments</b>		
Convertible loan note in Halo Therapeutics LLC	225,000	225,000
Less: treated as grant paid 2012	(224,999)	(224,999)
	<u>1</u>	<u>1</u>

Halo Therapeutics is a clinical-stage biopharmaceutical firm focused on developing innovative therapies for rare fibrotic diseases such as Duchenne Muscular Dystrophy. The programme has now merged with DART to ensure IP protection in anticipation of FDA approval. 2014 saw an application being made to the US regulatory body that included nonclinical study reports, pharmacokinetics, human safety and biomarker data from the DMD clinical program, and a comprehensive analysis and summary of the year's activity.

	2021 £	2020 £
<b>Other investments</b>		
1,371 Ordinary shares of £0.001	<u>1</u>	<u>1</u>

Pepgen Limited (company number 11170794) is a company focused on biotech research and development, to improve the delivery and effectiveness of exon skipping drugs as a way of restoring dystrophin. In April 2018, Action Duchenne was donated a number of shares in the company in recognition of previous support and funding to the University of Oxford, which amounted to a grant of £48,000 in April 2017. These shares are currently held at nominal value in the balance sheet on the absence of any reliable valuation information.

**7. Debtors**

	2021 £	2020 £
Trade debtors	42,858	7,500
Other debtors	4,441	9,976
Prepayments	<u>3,794</u>	<u>26,391</u>
	<u>51,093</u>	<u>43,867</u>

**ACTION DUCHENNE LIMITED**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

**8. Creditors: amounts falling due within one year**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Trade creditors	21,426	7,311
Accruals and deferred income	137,426	20,655
Tax and social security	-	47
Bank loan	5,833	-
Other creditors	<u>1,405</u>	<u>2,337</u>
	<b><u>166,090</u></b>	<b><u>30,350</u></b>

Deferred income included above relates to Science on Tour income £105,000 (2020 - £Nil) and Demelza project sponsorship income to January 2022 of £15,000 (2020 - £Nil).

**9. Creditors : amounts falling due after more than one year**

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Bank loans and overdrafts	<u>44,167</u>	<u>-</u>

**10. Trustees' expenses and indemnity insurance**

A Trustee may receive reimbursement of reasonable out-of-pocket expenses actually incurred in running the charity. In 2021, the total out-of-pocket expenses reimbursed was £Nil (2020 - £7,541) for travel and accommodation.

No indemnity insurance was paid by the company on behalf of the Trustees.

No Trustees received any remuneration from the Charity during the year.

**11. Control relationships**

The company is limited by guarantee with the liability of the members limited to £1 each in the event of a winding up. Consequently, no Trustee or group of Trustees has overall control of the company.

**12. Other professional services provided by the independent examiners**

In common with many other businesses of our size and nature, we use our independent examiners to assist with the preparation of the financial statements.

# ACTION DUCHENNE LIMITED

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

### 13. Restricted funds

The Charity has a number of restricted funds which are for future use.

The movements for the year are as follows:

	Newcastle CRF £	Lottery Fund £	Science on Tour £	Demelza £	Total £
At 1 April 2020	21,428	-	-	-	21,428
Donations / legacies / grants	50,000	75,560	-	5,000	130,560
Grants payable and research costs	(50,169)	(75,560)	(9,999)	(5,420)	(141,148)
Transfers from unrestricted funds	-	-	9,999	420	10,419
As at 31 March 2021	<u>21,259</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>21,259</u>

### Details of funds

Newcastle CRF – a consortia of seven UK Duchenne charities funds a senior lectureship at Newcastle University. Other members of the consortia have been invoiced for their share but due to Covid-19 and the ensuing economic climate they have not been paid. This obligation for other consortia members has been recognised in these financial statements and will be paid over promptly when received.

Lottery fund – funding received from the Coronavirus Community Support Fund, distributed by The National Lottery Community Fund, in recognition of our continuing work to support Duchenne families during lockdown and beyond. The project was successful delivered by 31 March 2021.

Science on Tour – supported by a consortia of pharmaceutical companies and the Garfield Weston Foundation. The project encompasses an extensive programme of 24 events over 12 months, visiting more than 20 towns and cities across the UK. Development of activities and materials which were carried out in phases in FY2020/21 using a just in time methodology to allow maximum flexibility to respond to COVID-19. The project is expected to be completed in 2021/22.

Demelza – this project has developed joint working between Demelza House Children's Hospice and Action Duchenne to support young people and their families. We plan to carry out reviews to collect information and data to help us decide how to improve the support for young people living with Duchenne and their families who are going through the transition process. The project is expected to be completed in 2021/22.

**ACTION DUCHENNE LIMITED**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

**14. Unrestricted funds**

	<b>General fund £</b>
At 1 April 2020	91,600
Income	363,778
Expenditure	(226,713)
Transfer	<u>(10,419)</u>
At 31 March 2021	<u>218,246</u>

The General Fund – Funds allocated to pursue the Charity’s aim of finding a cure for Duchenne, bring new medicines for Duchenne to the market and to enable us to continue to campaign for greater standards of care for those with Duchenne.

**15. Analysis of net assets between funds**

	<b>Fixed assets £</b>	<b>Current assets £</b>	<b>Current liabilities £</b>	<b>Long-term liabilities £</b>	<b>Total £</b>
Restricted funds	-	21,259	-	-	21,259
Unrestricted funds	<u>1,922</u>	<u>426,581</u>	<u>(166,090)</u>	<u>(44,167)</u>	<u>218,246</u>
	<u>1,922</u>	<u>447,840</u>	<u>(166,090)</u>	<u>(44,167)</u>	<u>239,505</u>

**16. Fund Transfers**

Transfer from unrestricted reserves to Science On Tour and Demelza relates to contributions to projects which setup costs have been incurred but have not been completed as at the year end.

**ACTION DUCHENNE LIMITED**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

**17. Analysis of resources expended**

	<b>2021</b> <b>£</b> <b>(12 mths)</b>	<b>2020</b> <b>£</b> <b>(17mths)</b>
Support costs:		
Bank charges and interest	1,216	1,317
Insurance	1,612	(710)
Wages and salaries	208,571	301,126
Printing, postage and stationery	7,380	6,184
Training, recruitment and other staff costs	3,371	16,497
Rent and rates	6,026	38,238
Computer costs	10,403	28,303
Storage	2,201	1,252
Telephone and internet costs	2,292	4,280
Depreciation	640	378
Trustees' meetings	-	7,541
Governance costs	15,650	11,467
Professional fees	6,188	-
Miscellaneous expenditure	<u>1,800</u>	<u>740</u>
	<b><u>267,350</u></b>	<b><u>416,613</u></b>

Grants totalling £76,232 were payable to 3 medical research institutions, as described in note 17.

Support and governance costs are allocated as follows:

	<b>Support and</b> <b>governance</b> <b>£</b>	<b>Direct</b> <b>costs</b> <b>£</b>	<b>Total</b> <b>£</b>
Scientific and clinical research and grants payable 80%	213,880	85,523	299,403
Fundraising 10%	26,735	14,988	41,723
Campaigning and education 6%	16,041	-	16,041
Improved management and medical care 4%	<u>10,694</u>	<u>-</u>	<u>10,694</u>
	<b><u>267,350</u></b>	<b><u>100,511</u></b>	<b><u>367,861</u></b>

The allocation has been determined on the basis of time spent by staff.



**ACTION DUCHENNE LIMITED**

**NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2021**

**18. Grants paid and future commitments**

The following institutional grants, in respect of research projects in furtherance of the charitable activities, were treated as grants payable during the year:

	<b>2021</b> <b>£</b> <b>(12 mths)</b>	<b>2020</b> <b>£</b> <b>(17mths)</b>
Grant – The University of Newcastle	50,000	50,000
Grant – CSO	-	9,063
Grant – UPPMD membership	-	1,810
Grant – University Hospitals Bristol NHS Foundation	-	12,260
Grant – Queen Mary University London	25,320	-
Grant – University College London	-	11,285
Grant – World Duchenne Organisation	912	-
Grant – MD UK	<u>-</u>	<u>25,000</u>
	<u><b>76,232</b></u>	<u><b>109,418</b></u>

The following payments in respect of research projects have been committed to but not provided for in the accounts:

	<b>2021</b> <b>£</b> <b>(12 mths)</b>	<b>2020</b> <b>£</b> <b>(17mths)</b>
Grant to The University of Newcastle	-	50,000
Grant to Queen Mary University London	<u>-</u>	<u>25,320</u>
	<u><b>-</b></u>	<u><b>75,320</b></u>

**19.Reconciliation of net income / (expenditure) to net cashflow from operating activities**

	<b>2021</b> <b>Total</b> <b>£</b> <b>(12 mths)</b>	<b>2020</b> <b>Total</b> <b>£</b> <b>(17mths)</b>
<b>Net surplus/(deficit) for the reporting period</b>	36,476	(23,538)
Adjustments for:		
Depreciation charges	640	378
Dividends, interest and rents from investments	(33)	(228)
(Increase) / decrease in debtors	(7,226)	40,606
Increase / (decrease) in creditors	<u>169,908</u>	<u>(104,328)</u>
<b>Net cash provided by (used in) operating activities</b>	<u><b>299,765</b></u>	<u><b>(87,110)</b></u>

**ACTION DUCHENNE LIMITED**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2021**

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**20. Analysis of cash and cash equivalents**

	2021 £ (12 mths)	2020 £ (17mths)
Cash in hand	<u>396,747</u>	<u>98,374</u>
<b>Total cash and cash equivalents</b>	<u><b>396,747</b></u>	<u><b>98,374</b></u>

**21. Commitments under operating leases**

The Charity had annual commitments under non-cancellable leases as set out below:

	2021 £ (12 mths)	2020 £ (17mths)
Operating leases which expire: within two to five years	<u>-</u>	<u>5,909</u>

**22. Loans and overdrafts**

	2021 £ (12 mths)	2020 £ (17mths)
Bank loans	<u>50,000</u>	<u>-</u>
Payable within one year	5,833	-
Payable after one year	<u>44,167</u>	<u>-</u>

The long-term bank loan is secured by fixed and negative charge over all of the assets of the Charity.

**23. Events after the reporting period**

The amounts due to the University of Newcastle and Queen Mary University were repaid in full during the 2021/22 financial year.